Collaborative representation: Narrative ideas in practice

by Sue Mann

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When I begin to reflect on the history that influenced my practices as a social worker within a hospital, there is one story that comes quickly to mind. It is not an amazing story. It is just a story that I like to tell myself as a reminder of why I have certain preferences in relation to ways of writing about the people who meet with me as a social worker.

The story – the man whose name I do not know

My first job twenty-five years ago as a social worker was in a general hospital where I worked for one year in a medical ward. On this occasion, I had been asked to see a man who had been admitted to the ward overnight because he was drunk, homeless, had no money or possessions. The impression I received from the referral was that as an elderly man all these factors added up to serious risk to his health. As is the case today, at that time social workers were under pressure to assist in 'emptying the beds' of non-urgent admissions by finding alternative accommodation. So, with some trepidation, if I remember correctly, I went to see this man to help him find supported accommodation. I was twenty years old and female. He was about 55/60. I had no idea what it meant to live on the street or to live a life under the influence of addiction. I had no idea how this man lived his life.

I was under the influence of the 'hospital story' - that the alcoholics and homeless admissions increased in winter as the weather got colder as they 'deliberately' sought a warm bed and three good meals in the hospitals. According to this story, these people's hospital admissions were frequently followed by a short stay in a hostel organised by the hospital, and then these people moved back to the park, hopefully in time for summer.

What I remember is that when I saw this man he was angry. He did not want to see me. He did not want to stay in hospital. He did not want to be organised into a hostel and instead he wanted money so that he could leave the hospital. Words like 'unco-operative', 'non-compliant', 'unreasonably angry' and 'manipulative' came to my mind. I went to the medical records and, encouraged by the tone of the medical registrar's notes, I added my own judgements - along the same lines. I'm sure I said something about 'not wanting to be helped' and 'nothing I could do'.

When I think about it now, I wonder if I didn't feel some degree of self-importance and certainty when I wrote those words. I suspect I had a sense of embracing my newly acquired professional role in being able to add my own evaluative comments to those already in the file. This was somehow especially so because I knew the notes were essentially 'secret'. They were seen only by other professionals. Patients in the hospital were not allowed access to them.

Later that morning the man left the hospital. Breaking the rules of the institution, he took his medical records with him!

How has this affected my practice? The journey of report writing

I have worked in lots of places and in different ways since then, but for the past five years I have worked in the children's section of a hospital. Most of the people I meet with are the mothers of either premature babies or sick children2.Very often they haven't asked to see me and have either agreed to meet with me on the suggestion of one of the nursing or medical staff, or have been advised that because of concerns in regard to the children, they are required to meet with me. Occasionally some women will themselves ask to meet with a social worker because of the distress they are experiencing in their lives. One of the struggles for me has been to find ways of respecting the stories that the women come with, stories of incredible courage, resourcefulness and imagination which so easily go unheard and unacknowledged. I wanted to find ways of making the women's voices louder, ways that could amplify the alternative stories of their lives and see them accomplishing a greater sense of influence over their experience of being in the hospital.

Introducing the medical records

Part of the organisational requirements and form of communication within a hospital system are the medical records kept on each patient. Sometimes these records develop a life of their own as one story can build upon another without check or comment from the very person central to the communication. Words that may be written in confidence on behalf of a woman, or even said in presumed confidence by the woman to a professional, can become the knowledge of all those who have daily access to the notes and sometimes to others who have no relationship to the person who has come to the hospital for care. The very last person to see these records or to have any knowledge of what is written in them, is the person who is most subject to the effects of what is written and with the least influence on the way the story is developed - the woman.

The journey of collaborative representation

In order to take some steps towards collaborative representation, what I began to do was to explain to people who met with me about the requirement I had to write in the medical records and to ask them if there was anything in particular they would like me to record on their behalf. I am not sure whether the surprise that I have encountered from people when I have suggested this has been because they were unaware that interactions with staff were being recorded, or whether they were surprised to be asked. I think for me, it has been this surprise that has had me paying more attention to this issue of representation, and has encouraged me to go further. It gave me the courage to begin to invite people to join with me in forming the words and the telling of the story that would go in their medical records.

Starting up - introducing the author

The way that it has happened so far, is that at the end of our meeting together I talk about the medical record and ask if the person concerned would like to participate in developing a record of our meeting. If they indicate that they would then this involves me leaving the person and going out to the nurses' bay to get the medical records3. With the records, I then return to the patients' room. Having often been sitting opposite the woman, I then sit next to her so that she can see what is being written and we begin the story4.

Usually I offer a brief starting comment that introduces the 'author' and explains how we have come to be meeting. I then ask a question, such as 'Where would you like to begin?' or 'What would you like the medical team to know about your experience so far?' or 'Is there anything in particular you would like the medical team to know so that they might be more helpful to you?'

Sometimes it is difficult for people to know where to start and I might offer a few alternatives, like 'You mentioned this and this and there was this other thing - are any one of those good places for you to begin?' Or if they still seem stuck I might suggest a starting place and choose something that seemed central to our discussions. Sometimes this leads to them identifying a different starting point and provides an opportunity to review their most immediate concerns.

Surprises along the way

What has surprised me has been how this process has enabled other conversations to develop that otherwise would have remained unspoken. At a medical team meeting I was asked to meet with a mother, I will call her Jane because there were some concerns that her baby's lack of weight gain could be due to 'failure to thrive' (this diagnosis carried with it implications of 'poor parenting' on Jane's behalf) rather than any sickness the baby may have been experiencing. One of the challenges for me has been how to make a respectful approach to women under these circumstances by not carrying judgements about parenting or worthiness into the room with me, while at the same time also respecting the concerns noticed by the medical and nursing staff. So, in this instance, I explained to Jane that I had been asked to meet with her because of worries about her baby not gaining weight. I asked her how things had been going for her and whether she would be happy to talk with me.

We then talked for about one and a half hours. Jane shared with me a history of struggle and determination to create a different picture for her own child than she herself had experienced as a child. She talked about separation from her family, isolation from other mothers, the hardship of maintaining part-time work and being a parent, and her fear of the stigma of being seen as a single parent 'bludging off the system'. I then suggested to her that this struggle and her commitments were not so easily visible to the medical team and that as I was required to write in the medical

records, I wondered whether she might like to share some of this with those who would have the medical care of her baby.

It was at this point that Jane said to me ‘Just don't put that I'm neurotic’. I said to her that this had been the last thing on my mind and asked her why she thought I might want to say something like that. This led to a new conversation about her experience of having an undiagnosed chronic physical illness that had been treated as a psychiatric issue as an adolescent, an illness which still had considerable effects on her energy and ability to lead a pain-free life. What this also meant was that we were able to write in the records a story of what she stood for in relation to her own child. We recorded what it had meant to struggle with ill health, isolation and lack of resources as well as Jane’s commitments and their history.

At the time I don’t think I was aware of what significance Jane may have attributed to having the opportunity to take charge of the representation of her life in the medical record. In hindsight I would have liked to have asked some questions about this experience.

In trying together to find the words that best describe conversations, other opportunities often arise. For another woman, Sharon, the search to describe what it feels like to be the only one who is caring for an unsettled baby led to finding new expressions to describe her experience. As we began to struggle to find a name for what it was like to be ‘stuck in the middle’ between her unsettled baby and her partner, we finally settled on ‘Manager of the Crying Company’. When we came up with this description of her role, Sharon smiled for the first time in our meeting. This naming opened up the possibility of other questions like: ‘Who else could be employed in the company? Are there any contract workers? Any people off on leave who need to be called back to work?’

This brought to the conversation an energy for solutions and a sense of hopefulness that had been absent before. The conversation was re-engaged with a clearer externalisation of the problem, more energy and at times a sense of fun.

At other times, trying to collaboratively find the words to include in the medical records has provided opportunities to more richly describe the influence of significant people in the woman’s life. The act of putting something into writing somehow engages people in noticing in more detail exceptions to the dominant stories of their lives.

Sometimes, significant meaning is drawn from the little things that people don't want included in the medical records - ‘don't put about my sister in’. When Judy said this to me, I realised that it was out of respect for her sister but was kind of surprised that Judy would think it was so important. But in re-telling this story here, what has emerged for me is a greater appreciation of how Judy was able to consider how her sister would be represented in the records and the care she was taking not to represent someone else’s life without them having a chance to collaborate. I wish I had been more curious about this at the time, because it seems significant to me now.

To write with the person with whom I am meeting has additional impact and occasionally, delightful surprises. I am reminded of the time when one woman asked, ‘Would you like me to sign that now?’. This was to me an exciting outcome. This woman clearly saw herself as the author of the story we had written and her signature was big and flourishing and took up at least three lines!

Its boldness still makes me feel like laughing with joy. Her invitation has led me to ask others if they would like to sign with me at the end of the record.

Opportunities to review practices

Engaging the women in these collaborative practices has also led to broader effects. Evelyn, was a woman in the hospital who had asked to see a social worker 'for the counselling'. We met many times during her baby's stay in the neonatal unit and when we came to write in the medical records she asked why it was that I was recording information about our conversations in her baby's records. Whereas once perhaps I would not have understood, this time I felt able to hear what she was saying. The stories she had shared with me were about her own experience as a woman and as a child. She was trying to convey to me that there would be implications for her and her partner in putting this story in her child's notes. Her concerns led me to think of other ways to communicate to the nursing/medical team in the Paediatric field and of how records in the social work department could be modified. I am so grateful for Evelyn's insistence and how this has led me to think differently about assumptions I may hold.

Finding ways to form a record of situations where violence is present in relationships has been difficult. I have been conscious of the need to protect the women legally so that if there is a later custody issue around the children, the history of abuse is recorded. Medical records also form the basis of the statistics for the hospital around the incidence of domestic violence in the community and influences how the hospital is seen to be responding to the issue which in turn has implications for funding.

However I also regret the effect that documenting violence in the medical records can have in some circumstances. I recall an instance when information became available more publicly in the medical record about the violence one woman had experienced. The outcome was that she was subjected to uninvited persuasion from others about leaving the relationship and expert opinion about what she should do from the other staff who had read the record. Other women have also talked about fears for their safety if their partners were to become aware through the medical record that they had talked about their experiences.

For one woman, her fears about the confidentiality of the record and her own safety led to a decision to write nothing about the relationship with her partner but instead to ask the Clinical Nurse Consultant whether she would spend time hearing this woman's story so that she could be in a better position to support and understand her experience while in the hospital. This is not a complete solution however, because although a record of this sort of action can be kept separately in the Social Work Department, this leaves the information out of the statistical record of the hospital and could ultimately affect the resourcing of services to women where violence is present in their lives. It has become clear though that grappling with the issue of how we as professionals represent other people's lives will allow opportunities to take issues up at an organisational level that otherwise may go unnoticed.

Why is this important?

Through writing this paper I have begun to ask more questions of myself about how I represent other people's lives. 'Why don't I involve everyone who consults with me in this kind of collaborative representation?', 'What makes it possible for me to engage in this practice?', 'What are some of the things that get in the way?'

Perhaps part of the answer to these questions is that one of the things I noticed when I first started working in hospitals was how hard it is to hang on to respectful practices. This is still something I have to attend to regularly. It is so easy to accept the invitations to have public conversations about private matters, to be drawn into language that is totalising of people's experiences, to let time constraints distract from preferred ways of working, and to step into being an expert not just with the women who meet with me but with other workers as well.

Reporting collaboratively in the medical records is for me a practice of respect. It is an opportunity to thicken the description of people's lives and to take a stand against practices of degradation. Using the words of the people who meet with me, whether they have actively participated in the recording of the record or not, has kept the notion of collaboration present in my work.

I have hoped that this has provided the opportunity for others who read the records to enter into an understanding of the person as 'more than the problem' and to make more visible their attempts to act against the problem. Trying to find ways to collaborate in relation to written representations is also for me a stand against thin descriptions of people's lives such as 'anxious mother', 'dependant relationship', 'attachment problems'. It is an opportunity to make visible the context of people's lives.

The journey away from assessment and towards partnership, hasn't been planned or predictable and has had some wonderful surprises along the way. I am continually surprised by the way the idea is welcomed and entered into by the women and how patient they are with me as I fumble with organisational requirements and as we struggle together to find the words to tell their stories. (The first time I did this we ended up tearing up the first two attempts and settling on the third!)

The man whose name I do not know – some reflections

In writing this paper, I have wondered what it might have meant had I not had the story that appears at the beginning of this article, in my life. What if the man whose name I do not know had not run off taking his medical records with him? Could the evaluative practices I engaged with in relation to

him, have gone unchecked and my confidence in making assessments of people's lives grown larger and more important?

I also wonder now why I did not feel vindicated by this man's actions - after all, he 'stole' the medical records from the nurses' bay (No patients allowed!), he left without signing a 'risk form' (very risky!) - his actions were so easily available to being interpreted as 'difficult patient', 'angry', 'non-compliant'. Instead, I recall feeling incredibly responsible for the carelessness I had shown in my language and judgements. I was very aware that none of the things I had written, although I felt they could be supported by notions of professional judgement, were things I could readily have said directly to this man. It seems strange to now be reflecting on how this story has survived so strongly in my memory. I wonder if this man is still living and what it might mean to him if I was able to tell him where the boldness of his actions have led me.

Notes

1. This paper was written when I was still working as a hospital social worker. Since I wrote this paper I have left this position and am now working as a counsellor at Adelaide Central Mission. I can be contacted c/o Dulwich Centre Publications.

2. I am aware that the stories of men don't appear in this account. I do see the fathers of babies and children and men on other wards but not frequently. Most of my experience involves working with women, although I am hoping to extend the use of these collaborative practices.

3. I wouldn't like to give the impression that every person with whom I meet and suggest collaborating with engages with the idea. I have had responses like 'it's none of their business', or 'I don't care' or 'I'm not interested'. Sometimes this leads to other conversations but at other times I am left to write on behalf of the person. My intention is to let people know that there is a medical record and that I have a requirement to report my meeting with them and that they can join with me in the writing if they wish.

4. I am aware of the fact that the medical records are the property of the hospital and that normal practice involves having a doctor present to interpret the contents for a patient. To preserve the confidentiality of other professionals' contributions to the record, I had to consider starting the joint writing on a new page, deliberately covering preceding entries or occasionally bringing in blank pages which we would write on and then add to the medical record at a later time.

5. The names of all the women who consulted with me have been changed.